

Abstract 423

TITLE: A Non-Name-Based System for HIV Surveillance in Massachusetts

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ISSUE: Recent decreases in new AIDS cases reported in Massachusetts led to implementation of a non-name-based surveillance system for HIV infection. The purpose of the program is to track the scope and trends of the HIV epidemic in Massachusetts. Information gathered will allow better targeting and evaluation of HIV prevention efforts and estimate needs for HIV prevention and treatment services.

SETTING: Commonwealth of Massachusetts

PROJECT: An active surveillance system was implemented building upon the current AIDS reporting system. Unlike AIDS reporting which is done by name, a decision was made with significant community involvement that HIV reporting would be by an identifier generated by the reporter. Several other states implemented non-name systems but a number of components make this system unique: (1) there is no intermediary data collection; (2) relevant information is collected at the same time; (3) laboratory reporting is not an essential requirement; (4) codes are created only for those testing positive. Regulations regarding disease reporting were changed to require the MDPH be notified of all HIV-infected individuals by licensed providers and facilities. Reporting is done by providers upon receipt of test results and includes newly diagnosed infections as well as individuals already in care. Information reported includes the case code, demographics, patient risk history, facility of diagnosis, laboratory data and treatment/services referral information. The case code is constructed of the first two letters of the first name, number of letters in the last name, gender, date of birth, last four digits of social security number and zip code of residence. Upon receipt of a case, MDPH staff check the report against existing databases for duplicates and if no duplicates are identified the case is entered into the an Access[®]-based data management system. In addition to provider reporting, laboratories performing HIV tests provide MDPH with information regarding HIV-positive test results, including date the sample was drawn and the provider who requested the test. MDPH follows up with providers to ensure that case report forms are completed. An evaluation of the surveillance program is planned for 2000. The focus of the evaluation will be: (1) completeness of data elements in the non-name identifier; (2) identification of duplicate cases; (3) timeliness of newly diagnosed HIV infection cases; (4) completeness of reporting.

RESULTS: Over 150 clinical sites and forty laboratories have been trained regarding HIV reporting requirements. Since program initiation, case reporting has been high and completeness and quality of the data is excellent. An additional benefit has been an increase in AIDS reporting due to increased awareness of reporting requirements.

LESSONS LEARNED: A non-name-based surveillance system can be implemented for HIV reporting. Intensive training regarding reporting requirements is necessary. Unique aspects of the MDPH, including a provider-based reporting system and a lack of intermediary steps have facilitated the process and will help to ensure the long-term success of the program.

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